

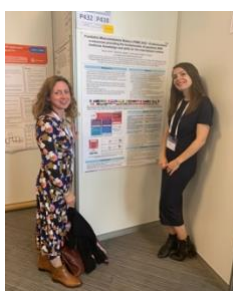


Welcome to our December 2022 e-Newsletter and to our expanding global community!

Goodbye 2022!

What a long, strange trip 2022 has been! At some point in this year many of us started to resume our lives in a fashion that closely approximates the normal we knew before the pandemic.

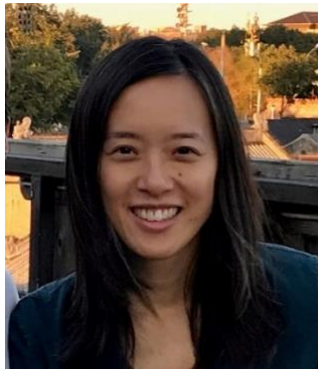
Whilst we are more easily working from home and having more online meetings, many of us have resumed travel (with all its new challenges) and started to regain the joy of face to face meetings. The PReS, ACR and BSR meetings in September and November were wonderful occasions for us to meet up again and rediscover the joy and warmth of in person meetings. Indeed, the Global Task Force, which was convened just before the pandemic struck, had rarely opportunity to meet formally and in person. So, it was a few months after our third birthday that we managed to fill a conference room in Prague to capacity and meet one another face to face to carry forward our goal to positively impact the lives of children and families from across the globe who are living with musculoskeletal conditions. What a pleasure it was to feel the strength of our common cause and hear reflections from literally all over the globe.



Even better were the poster tour and corridor discussions and the varied social interactions on and off the conference campus.

The endorsement of the PReS community and leadership for the mission of the Global Task Force and the PMM suite of educational tools was clear and global health issues were a golden thread running through many, if not most, plenary sessions.

While no formal Task Force meeting was held at ACR, a strong emphasis on global health has become part and parcel of the ACR annual conference. The ACR Global Rheumatology Summit convened by **Dr. Evelyn Hsieh** explored global health topics with truly world class



perspectives from a truly representative faculty of experts in paediatric and adult rheumatology from 19 countries, many of them members of the Global Task Force! The Opening Keynote Panel tackled the complex and intertwined challenges of Climate Change, Conflict and Migration and how these crises impact human health and disease across the globe. Panellists brought the unique perspectives of academia, intergovernmental and non-governmental institutions to highlight the multi-sectoral response required to address these challenges. The summit also featured sessions on access to care and medications, building equitable global partnerships, and advocacy. It showcased innovative mentorship and training models around the world and addressed the burden and harm of wasteful medical care in different healthcare settings. Complex cases of idiopathic inflammatory myopathy submitted from around the world were also discussed and debated by international myositis experts in a lively *Global Meet the Experts* session. Finally, we would be remiss not to celebrate and congratulate Dr. Nicola Ruperto, pediatric rheumatologist from Italy, who was awarded this year's Distinguished International Rheumatology Professional Award and acknowledged with a heart-warming video at the beginning of the Summit.

Claudia, Helen and I would like to take this opportunity to thank and applaud our Task Force Steering Committee members for their dedication and hard work as well as their unquestionable commitment, achievement and impact. We have achieved a great deal over the last year and look forward to more in the next year. Come on 2023, we are ready for you !

Australia holds Parliamentary Inquiry into childhood rheumatic diseases

The Australian House of Representatives Standing Committee on Health, Aged Care and Sport has conducted an Inquiry into childhood rheumatic disease in Australia. The terms of reference of the Inquiry included the prevalence of diseases, research into causes, the impacts on children and their families (including health, social, educational and economic impacts), access to medical services, workforce capacity and training, best practice quality of care and treatments, and awareness of the diseases among healthcare professionals and the broader community.

The Juvenile Arthritis Foundation Australia (JAFA) campaigned for this ground-breaking inquiry given the lack of access to diagnosis, care and treatment for children in Australia with rheumatic diseases and their families.

The Standing Committee received over 130 written submissions, including from the Global Task Force and heard evidence in public hearings from medical professionals and families alike. These submissions, along with the terms of reference and the Standing Committee's

interim report can be found at

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases.

The Standing Committee's interim report was tabled in Federal Parliament on 31 March 2022 and made 15 comprehensive recommendations for reform in Australia. Most notably, the first recommendation was to triple the workforce by 2030 in order to bring Australia's workforce to minimum international standards. Further recommendations included establishing multidisciplinary centres of care in all capital cities, outreach care for regional and rural areas, greater education for GPs together with the wider medical professional, schools and community, ensuring access to disability support and new medications, and the establishment of a national registry.

Jafa and the Australian Paediatric Rheumatology Group have combined forces to lobby for the adoption of the recommendations which would revolutionise the access to care and treatment for children with rheumatic diseases and significantly reduce the burden of these diseases.



<https://www.jafa.org.au/jafa-thanks-prime-minister-albanese/>



On November 25, in response to a request from Jafa, the Prime Minister, Mr Anthony Albanese, hosted a landmark afternoon tea at The Lodge in Canberra for 13 children with arthritis, their parents and Jafa representatives to help boost national awareness of juvenile arthritis. Prime Minister Albanese spoke with the children and listened to their

experiences of what it's like living with daily pain, striving to keep up at school, and the challenges of accessing the medical care and support they need.

The Global Task Force congratulates JFA and the Australian paediatric rheumatology community for all their hard work and we will add our support wherever we can to build on the foundations to ensure better care for children and their families. This is an excellent and powerful exemplar of advocacy and partnership in action that has transferable value and impact to the rest of the world.

PRoS Global Health Research Fellowship Report from Dr Waheba Slamang Revising the WHO EML Joint Diseases in Children



It has been an honour and privilege to work with Helen Foster, Chris Scott and members of the Global Task Force on revising the World Health Organisation Essential Medicines List (WHO EML) to reflect standard care for children with rheumatic diseases.

Following feedback from the WHO EML committee on the previous Task Force submission in 2021, we aimed to provide the WHO EML secretariat with a clearer perspective on the role of triamcinolone hexacetonide, tocilizumab and anakinra in the modern management of JIA and the need for their inclusion in the WHO EML.

We formulated a 'Letter of Response' to the committee's questions, along with a set of documents to meet the requirements for re-submission. Our collated document includes a narrative review of the evolution in understanding of JIA and its management (which forms an additional evidence base for the applications); a [published survey](#) providing information about the challenges to the care of children with JIA (complementary to our [2021 survey](#) about the medicines considered important for inclusion); with invaluable letters of support from patient networks and professional organisations lending further credence to our application. It is anticipated that these documents will become available as a template to assist with future applications to national EML committees in countries where these medicines are not yet available.

This project truly embodied the concept of 'working better together' as we engaged the rheumatology community worldwide to express a clear case of need; the teams who worked tirelessly to compile the first submission, Nicola Smith for compiling and analysing the surveys, Tavi Cuevas for pharmacy input (and at short notice!), all survey respondents, patient and professional organisations amongst others providing letters of support. The WHO EML secretariat have been supportive and instructive so we wish to thank them for their input.

I am especially thankful to have had the funding support from PRoS, which allowed for dedicated time to be spent on this important project, and am grateful to SHARE for providing useful data references.

We are now ready to submit the updated applications – we have our fingers and toes crossed that these will meet with success. We will hear in 2023 and will keep the community updated.

Strengthening health systems for musculoskeletal health in low and middle-income countries – Professor Andrew Briggs



The burden of disease attributed to musculoskeletal (MSK) conditions disproportionately affects people in LMICs. This is attributed to a confluence of factors including increasing prevalence with a more rapidly ageing population, population growth and more restricted access to effective prevention and control interventions. While health systems strengthening responses to arrest the burden attributed to MSK impairment are emerging in high income settings¹, with global-level guidance is now also available², these strategies may not necessarily be transferable to LMICs. An international team of researchers from across geographies and disciplines have examined this issue³ and included members of the Paediatric Global MSK Task Force. They undertook

secondary analysis of qualitative data to specifically interrogate themes relevant to context and priorities for MSK health system reform in LMICs and coupled these data with analysis of health policies for integrated management of non-communicable diseases. The team examined data from nine LMICs: Argentina, Bangladesh, Brazil, Ethiopia, India, Kenya, Malaysia, Philippines and South Africa.

Five key themes were identified, including:

- (1) MSK health is a low priority in LMICs compared with other health priorities, including NCDs more strongly associated with mortality and communicable, maternal, neonatal and nutritional diseases;
- (2) social determinants in LMICs adversely affect MSK health;
- (3) there is a need for community-based screening of MSK health impairments, particularly in children;
- (4) economic constraints restrict system capacity to direct and mobilize resources to MSK health; and
- (5) there is a need to build local research capacity in MSK health.

Among the 12 health policies examined, none had an explicit priority focus on MSK health. The authors present findings as key challenges, opportunities and prioritised for health systems strengthening in MSK health in LMICs. The paper is published in the journal [Health Policy and Planning](#) and a project report is available. <https://gmusc.com/systems-strengthening-in-lmics/>.



Towards a global strategy to improve musculoskeletal health



Curin University

UNIVERSITY OF SYDNEY

HealthSense

UNIVERSITY OF TORONTO

UNIVERSITY OF TORONTO

CMCC

SDU

UNIVERSITY OF TORONTO

Subject: your views on the global musculoskeletal strategy

Last year, the report, [Towards A Global Strategy To Improve Musculoskeletal Health](#) was published by the Global Alliance for Musculoskeletal Health (G-MUSC). It outlines a roadmap for health systems internationally on 'what' can be done to improve musculoskeletal health and rheumatic diseases, and importantly 'how', across contexts and settings. The roadmap was co-designed by the global community, comprising 678 individuals and 116 organisations from 72 countries. Originally published in English, the report has now been translated into Arabic, Simplified Chinese, Hindi, Brazilian Portuguese, Latin American Spanish and Swahili. Access the translated reports [here](#). **To support dissemination and advocacy efforts, we would like to understand our stakeholders' perspectives on the strategy. Please consider sharing your views through a 3-5 minute survey, available in**

- [English](#)
- [Arabic](#)
- [Brazilian Portuguese](#)
- [Hindi](#)
- [Latin American Spanish](#)
- [Simplified Chinese](#)
- [Swahili](#)

The evaluation is approved by the Curtin University Human Research Ethics Committee (HREC: HRE2022-0404)



Towards a global strategy to improve musculoskeletal health



Now in Arabic, Simplified Chinese, English, Hindi, Latin American Spanish, Swahili and Brazilian Portuguese.

It is time for health systems internationally to respond to the rising burden of musculoskeletal impairments.

<https://tinyurl.com/globmsk>

1. Briggs AM, Persaud JG, Deverell ML, et al. Integrated prevention and management of non-communicable diseases, including musculoskeletal health: a systematic policy analysis among OECD countries. *BMJ Global Health* 2019;4:e001806. DOI: 10.1136/bmjgh-2019-001806.
2. Briggs AM, Huckel Schneider C, Slater H, et al. Health systems strengthening to arrest the global disability burden: empirical development of prioritised components for a global strategy for improving musculoskeletal health. *BMJ Global Health* 2021;6(6):e006045. DOI: 10.1136/bmjgh-2021-006045.
3. Briggs AM, Jordan JE, Sharma S, et al. Context and priorities for health systems strengthening for pain and disability in low- and middle-income countries: a

secondary qualitative study and content analysis of health policies. Health Policy and Planning 2022. DOI: 10.1093/heapol/czac061.

Treating to Target for Childhood SLE: A Global Collaboration

Dr Eve Smith



Then cSLE International Treat-to-Target (T2T) Task Force came together on the 21st/22nd November in Liverpool, UK, hosted by Eve Smith and Michael Beresford, from Alder Hey Children's Hospital / the UK's only Experimental Arthritis Treatment Centre for Children (EATC4Children) University of Liverpool. T2T is part of routine clinical care in many areas of rheumatology, and there is increasing interest in adopting use of T2T in childhood and adult-onset SLE, as a means to aggressively controlling disease activity, preventing organ damage, and improving health related quality of life.

The principle aim of November's meeting in Liverpool was to discuss and agree methods for a future cSLE T2T clinical trial. Prior to this, the cSLE T2T Task Force has undertaken a series of Delphi surveys and on-line consensus meetings to agree principles and recommendations underpinning a T2T approach and paediatric appropriate target definitions. The task force includes representation



from PReS, CARRA, the UK JSLE Study Group and the British Association for Paediatric Nephrology (BAPN) with cSLE experts from all over Europe, Canada, USA, South America, South Africa and India, including members of the Global Task Force for Paediatric Musculoskeletal Health. The Task force works closely with three patients and a parent representative who were an integral part of the meeting and provided key insights into how the study design could be improved for patients. Eve has recently been awarded the UK Medical Research Foundation Emerging Lupus Leaders Prize and will use the prize funds to support the work of the Task Force, with the aim of accelerating progress towards development of a cSLE T2T clinical trial!

An update on PMM Editorial Board and Global Task Force meeting at PReS - Dr Nicola Smith, PMM Project Officer

Members of the PMM Editorial Board and Paediatric Global MSK Task Force held a meeting at the PReS annual congress in Prague on 22nd September 2022 with more members joining remotely. There was wide representation including paediatric rheumatologists at all grades, allied health, nursing and parent advocates.

Dr Sharmila Jandial (PMM Clinical Liaison) provided an update on the wide impact and reach of PMM with additional updates from Prof Helen Foster and Prof Chris Scott on key Task Force projects and steps moving forward to further increase engagement.

Group discussions highlighted target audiences for PMM and the Global Task Force being very similar (Family health unit/Community Health Workers, Allied Health, Nurses, General Paediatricians, Medical students, Primary care, Emergency medicine, Orthopaedics, Ministry of Health, Parent organisations/ Patient support/advocacy groups, Training institutions).

Ways to further reach such target audiences were discussed;

- Engaging with nurses and allied health working with doctors around the world who are contributing to PMM.
- Engaging with students and trainees through training institutions and networks
- Engaging with national charities around the world
- Using social media to promote key messages about PMM and the Task Force.
- Developing links with and utilise 'champions' in each country/organisation to help dissemination
- Key messages to be promoted
 - The existence of PMM and the Global Task Force and how to access educational resources on the respective websites (<https://www.pmmonline.org> and <https://www.pmskglobal.com>)
 - Opportunities to connect and engage in the on-going work of PMM and the Global Task Force
 - Highlight that PMM and access to the Global Task Force website is free, open to all and developed by clinicians for clinicians to facilitate engagement of target audiences.

Finally, Prof Claudia Magalhaes led discussions about how we can further work together. The regular monthly remote Steering Group meetings will follow up on the action points. There will be PMM Editorial Board and Global TF meetings at each PReS annual meetings



A structured training programme from Thailand to increase Paediatric Residents' Competency and Confidence During a 4-week Paediatric Rheumatology Rotation.



Prof Sirirat Charuvanij

Dr. Maynart Sukharomana

Virtual Poster Presentation at the ACR Convergence 2022 from the Division of Rheumatology, Department of Paediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand. Key Points:

- Due to the scarcity of paediatric rheumatologists in Thailand, general paediatricians are mostly the first to encounter patients with musculoskeletal (MSK) complaints.
- We evaluated the structured educational activities of knowledge, MSK examination skills, and confidence among paediatric residents who attended the 4-week paediatric rheumatology rotation by 25-item multiple choice questions (MCQ) covering the essential topics in paediatric rheumatology, MSK examination using 18 items from Thai pGALS and a questionnaire to evaluate experiences and level of confidence in paediatric rheumatology clinical practice.
- The structured curriculum included MSK examination teaching at the first paediatric rheumatology clinic, followed by two sessions of interactive lectures including “approach to arthritis” and “emergency in paediatric rheumatology”, 4 sessions of weekly topic review in paediatric rheumatology, and involvement in in-patient and out-patient paediatric rheumatology consultation.
- The Paediatric Musculoskeletal Matters (PMM) website (which is developed by a global expert team and supported by Paediatric

Rheumatology European Society (PReS)) has been used as a comprehensive educational resource for self-study

<https://www.pmmonline.org/doctor>

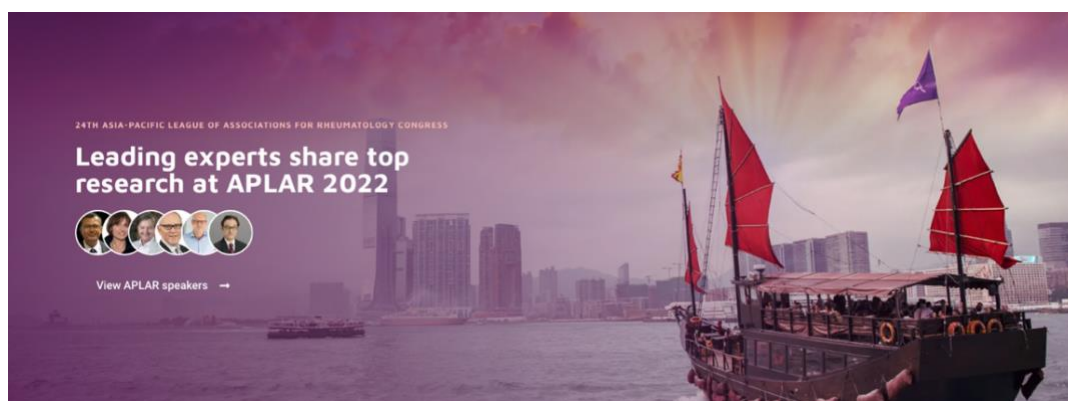
- 35 paediatric residents (28 F: 6 M) enrolled as a preliminary result. The median (IQR) post test scores in knowledge and MSK examination skills significantly increased from the pre-test scores, $p < 0.001$.
- The level of confidence in paediatric rheumatology clinical practice significantly increased at the end of the rotation
- The exit survey revealed that most residents agreed that teaching of paediatric rheumatology should be enhanced in paediatric residency training.
- We believe that this research will help contribute to the improvement of paediatric rheumatology education in Thailand and in the global community.

The abstract can be viewed in ACR Convergence 2022 Abstract Supplement:

<https://onlinelibrary.wiley.com/toc/23265205/2022/74/S9>

or ACR abstract website <https://acrabstracts.org/.../the-structured-curriculum.../>

A Report from APLAR 2022 – Dr Elizabeth Ang (Singapore) on behalf of the Paediatric Special Interest Group



For the first time since its inception at APLAR 2018 in Brisbane, the Paediatric Special Interest Group (SIG) of the Asia Pacific League of Associations for Rheumatology (APLAR) met in Hong Kong on 7th Dec 2022, at a combined in-person and virtual meeting. The APLAR covers 32 national rheumatology associations that span Iran and Saudi Arabi in the Middle East, Mongolia in Asia, to Australia and New Zealand in the Oceania, and many nations in between!

Previous Paediatric SIG meetings in the pandemic years had been completely virtual, and included 6 webinars where cases were presented, and the diagnosis and management of

rheumatologic conditions were discussed, with special consideration for the unique socio-cultural and resource variations faced by patients and providers in the region that spans almost half the hemisphere, and over 10 time zones!

The meeting was co-convened by Professor Sumaira Farman (Pakistan) and Dr Elizabeth Ang (Singapore), and we were pleased to have other in-person representatives from Hong Kong, India, Iran, Japan, Malaysia, the Philippines, Saudi Arabia, Thailand, Taiwan, and a special appearance from Dr Chris Scott himself. Virtual attendance came also from Australia, Bangladesh, Malaysia, New Zealand. We identified our priorities for:

1. establishing a directory of Paediatric Rheumatology providers to gain better understanding of the current workforce,
2. creation of guidelines for the management of JIA in the Asia Pacific,
3. increasing representation among APLAR activities by way of a regular Paediatric section of the International Journal of Rheumatic Diseases (IJRD, the formal journal of APLAR),
4. pushing (!) and planning for a dedicated Paediatric plenary session at future APLAR meetings, with dreams of a Paediatric-focused course and fellowships for providers in the region
5. establishing regional networks for collaborative research

There is much work to be done, with so many challenges! But the last 2 years have seen us gain excitement and momentum. We can't wait for more of us to meet in person in Chiang Mai, Thailand for APLAR 2023. We also welcome Paediatric-specific submissions to the journal! (<https://onlinelibrary.wiley.com/journal/1756185X>)

The Paediatric Task Force 'call for action'

Background

- The Paediatric Task Force for Global Musculoskeletal Health was set up in 2017 as part of the Global Alliance for Musculoskeletal Health (G-MUSC) and acknowledges the importance of a 'life course approach' to optimising musculoskeletal (MSK) health across the ages.
- We are a virtual global community and open to all: clinicians (doctors and allied health professionals) from paediatric rheumatology and orthopaedics, patient and consumer groups, professional societies, healthcare planners and policy makers, non-health professional groups, research consortia, industry (e-technology, pharma).
- There is great enthusiasm to 'work better together' to improve the lives of children through raising awareness amongst health care planners and policy makers that more needs to be done
- We work in partnership with the Pediatric Rheumatology European Society (PReS), The International Pediatric Orthopedic Society (IPOS) and the Paediatric Musculoskeletal Matters (PMM) learning e-platform.

Our Aims

To Raise Awareness

- About the *many* children and young people around the world with MSK problems
- About the considerable long-term impact of *untreated* MSK conditions starting in early life: *impact* on young people, their families, carers and society
- That many conditions are *treatable*; long term disability can be avoided thus reducing 'cost' to individuals and society

To Identify and Promote tangible exemplar solutions to better access to 'right' care

- Models of clinical care and care pathways
- Education and training for the workforce
- Patient and public involvement and engagement

To Promote healthy joints and bones

- Through lifestyle (e.g diet, exercise) to prevent obesity
- Reduce the risk of injury
- Reduce the long term risk of osteoarthritis and osteoporosis

Our Structure and Membership

- The Paediatric Task Force works in partnership with organisations to address global challenges in paediatric MSK health
- We have a chair and 4 co-chairs, steering committee with multiprofessional representatives from paediatric rheumatology, paediatric orthopaedics and including parent and patient organisations.
- We have 12 'regional representatives' from around world (clinicians, allied health and parents).
All roles are voluntary and non remunerated.

Paediatric Global MSK Task Force <https://www.pmskglobal.com>

Pediatric Rheumatology European Association (<https://www.pres.eu>)

Paediatric Musculoskeletal Matters (<http://www.pmmonline.org>)

Follow us:

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